Hot Topic

Sheehan's syndrome: no milk? Think Sheehan's!

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ORIGINAL

What is Sheehan's?

Sheehan's syndrome (postpartum hypopituitarism) was first described in 1937 by Harold Leeming Sheehan (1900–1988). He described it as pituitary gland necrosis following postpartum haemorrhage or hypovolemia (Sheehan 1937).

There are many questions regarding the pathophysiology behind Sheehan's syndrome and there have been calls for further research into whether hypoperfusion is enough to explain the tissue necrosis, or whether factors such as anti-pituitary antibodies or small cella size are also involved (González-González & Borjas-Almaguer 2018). Indeed, a case reported in 2020 had no inciting factors, such as haemorrhage or hypovolemia (Sethuram et al 2020).

The pituitary gland

The pituitary is a pea-sized gland found inside the *sella turcica*, which is a bony hollow within the base of the skull, level with the bridge of the nose. The pituitary is known as the 'master gland' due to its vital role in controlling hormones essential for life and bodily function (Society for Endocrinology 2018).

In pregnancy, the pituitary gland becomes physiologically enlarged in order to respond to increased hormonal demands and can reach twice its usual size. The anterior pituitary does not have its own direct blood supply and so is particularly vulnerable to damage during this time (Dahan & Tan 2015). Around a third of those with severe postpartum haemorrhage experience a degree of hypopituitarism, however typically 75 per cent of tissue needs to be damaged for a clinical presentation (Shivaprasad 2011).

In recent years, attention has shifted away from Sheehan's syndrome in developed countries as a result of advances in obstetric care. A 2011 Icelandic study found a prevalence of 5.1 in 100,000. It concluded that this figure was surprisingly high and likely to be underestimated due to delayed diagnosis or misdiagnosis (Kristjansdottir et al 2011).

In developing countries, such as India, the prevalence has been found to be 3100 in 100,000 (Shivaprasad 2011). Symptoms may appear in the initial postnatal period *(acute)* or over time *(chronic)* depending on the degree of tissue damage (Hao et al 2012). In developed countries the time to diagnosis for women with chronic Sheehan's syndrome is 9 ± 9 years whereas, in developing countries, it is 20 ± 8 years (Jose et al 2019).

Symptoms of Sheehan's syndrome

Women with Sheehan's syndrome have varying levels of pituitary dysfunction (Shivaprasad 2011), the most life-threatening being hypocorticolism (lack of the hormone cortisol) (Dahan & Tan 2015). This is caused by adrenocorticotrophic hormone (ATCH) deficiency; ATCH is released by the pituitary (Shivaprasad 2011). It is vital that this is detected and treated early with glucocorticoid replacement to avoid risk of coma or death in adrenal crisis (González-González & Borjas-Almaguer 2018). Risk of adrenal crisis may present in the postpartum period or much later when the woman undergoes a stressor, such as surgery or illness (Shivaprasad 2011).

Regardless of acute or chronic presentation, however, the most frequently documented symptom in the early postnatal period is failure to lactate or difficulty lactating (Sheehan 1937, González-González & Borjas-Almaguer 2018). This has been described as a key clue to early diagnosis, along with amenorrhea (lack of menstruation) (Schrager & Sabo 2001, Shivaprasad 2011). This may also be accompanied by headache, visual disturbance, vomiting, diarrhoea and high urine output (Dökmetaş et al 2006, Shivaprasad 2011).

Although rare in countries such as the UK, early diagnosis remains vital as Sheehan's syndrome is associated with reduced quality of life and potentially life-threatening complications (González-González & Borjas-Almaguer 2018). It is also relevant when clinicians are presented with women who may have given birth outside the UK, in countries with less advanced health care, where there is a significantly higher incidence (Shivaprasad 2011).

Case studies of three women with Sheehan's syndrome

The aim of this work was to communicate the early postnatal experiences of women with Sheehan's syndrome in the UK. Three women with Sheehan's syndrome in the UK were connected via The Pituitary Foundation and a Sheehan's syndrome social media page and all had an interest in sharing their experiences for the benefit of future patients (Table 1).

The women were sent a form to complete their timeline of events, with space for their own narrative on their experience. There was also informal communication regarding experiences and outcomes over email. Contrasts in their journeys to diagnosis, and their reported health, wellbeing and social outcomes, were highlighted to inform health providers involved in early postnatal care.

The experiences of three women with Sheehan's syndrome in the UK

Signs and symptoms of Sheehan's syndrome

All three women experienced failure to lactate, blood loss requiring transfusion and feeling unwell during their time as maternity inpatients.

Mother A and Mother B (who both had acute Sheehan's syndrome) experienced visual disturbance, hypotensive episodes and reported being unable to sleep.

Mother A, who was diagnosed with Sheehan's syndrome on day 5, also experienced headaches, vomiting, tachycardia, pyrexia and diabetes insipidus.

Table 1. Summary of cases.

Cases	**Mother A** NHS Scotland Acute Sheehan's syndrome	**Mother B** NHS England Acute Sheehan's syndrome	**Mother C** NHS England Chronic Sheehan's syndrome
Background information	2015 35 years Baby following previous miscarriage Low-risk pregnancy Existing high blood pressure On low-dose aspirin Full-time financial services	2014 28 years Primigravida Low-risk pregnancy Full-time allied health professional	2019 39 years In vitro fertilisation (IVF) baby following previous miscarriage Low-risk pregnancy Group B Strep positive Full-time charity professional
Labour and early postnatal history, days 1–5	35+4 waters broke Episiotomy in theatre Atony of uterus, baby in NICU Blood loss requiring two units of red blood cells (RBC) Referral to endocrinologist Day 5 diagnosed with Sheehan's syndrome	40+8 Community Midwife Unit 3rd degree tear Ambulance to general hospital Emergency surgical repair of tear Hypotensive episodes 70/40 Blood loss requiring two units of RBC No referral Day 5 discharged home – no diagnosis	39+1 waters broke Induced 40-hour labour Emergency c-section Return to theatre for repair to extension on right angle Blood loss requiring three units of RBC, two units of fresh frozen plasma (FFP) No referral Day 3 discharged home – no diagnosis

Clinical care

Mother A was closely monitored by obstetric staff and referred to endocrinology. She was diagnosed with acute Sheehan's syndrome on day 5 postpartum. She commenced glucocorticoid replacement immediately. She remained in hospital in a transitional care ward until day 9, under the care of an endocrinologist.

Mother B and Mother C were reassured that a delay in milk is normal following blood loss. Mother B was advised that her visual disturbance was likely due to the tramadol she was taking for analgesia. She was referred for a routine outpatient ophthalmology appointment once discharged home.

Short term history

Due to her prompt diagnosis and immediate glucocorticoid replacement, Mother A was no longer at risk from a life-threatening adrenal crisis.

Mother B was followed up by the community midwifery service once home. She continued to exhibit visual disturbance and lack of milk production. After becoming unsteady with vomiting and diarrhoea, she was advised to see her general practitioner (GP). The GP made another referral to outpatient ophthalmology. At day 13 postpartum, Mother B awoke in the later stages of adrenal crisis. She was admitted via ambulance to the accident and emergency resuscitation unit. She was then admitted to critical care following a tonic-clonic seizure and sedated. She was diagnosed with hypopituitarism, thought to be caused by an undetected pituitary adenoma (her CT scan showed an enlarged pituitary). She stayed in hospital for another 13 days, until an MRI showed a pituitary clear of an adenoma. She left hospital on glucocorticoid and thyroid replacement, with the diagnosis of postpartum hypopituitarism, later confirmed as acute Sheehan's syndrome.

Mother C (chronic Sheehan's syndrome) received one more visit than standard postnatal care in the community. She continued to exhibit failure to lactate and feeling unwell. She experienced low mood and anxiety. She visited two private breastfeeding consultants and her GP prescribed prolactin tablets. She traced her postpartum history and symptoms to Sheehan's syndrome. After 18 months she was diagnosed with chronic Sheehan's syndrome after blood tests and an MRI by a private endocrinologist.

Impact on mental health and wellbeing

All three women reported anxiety and low mood as a result of their experiences. They recounted feeling isolated as mothers with a rare condition, along with feelings of failure and grief regarding their inability to breastfeed. Both Mother A and B shared their sadness at not being strong enough initially to confidently feed or hold their babies.

Mother B was also diagnosed with depression and post-traumatic stress disorder (PTSD). She reported feelings of grief that she was separated from her baby for the time in hospital following her adrenal crisis. Following her tonic-clonic seizure she developed severe musculoskeletal pain.

Mother C was referred to her GP for possible postnatal depression. She described the uncertainty and concerns of her body changing due to undiagnosed hormone deficiencies such as amenorrhea, hair loss, weight gain and ongoing exhaustion.

All three women described the significant effort required to understand and manage a complex medical condition. In addition, they all expressed their feeling of lack of support and understanding of their condition by health care staff.

Social outcomes

Mother A returned to her career in financial services. She was able to conceive using intrauterine insemination (IUI) treatment and gave birth to a healthy baby in 2020.

Mother B initially returned to her career as an allied health professional but resigned one year later due to her health. Both Mother B and her husband wished to have another biological child but felt they could not proceed with fertility treatment due to the trauma of their previous experience. Mother B expressed her grief regarding both not having another child and the loss of her career.

Mother C has not yet returned to her career as a charity professional. She and her husband have two remaining IVF embryos that they wish to use. However, Mother C reported that her periods have not returned and she is lacking the energy to proceed with this process at present.

Patient narrative

All three women reported times when they felt misunderstood, or not listened to, when raising their concerns with health care staff. Mother A reported that, during her first three days postpartum, the staff made her feel there was nothing wrong. Mother B felt that staff on the maternity ward seemed too busy and stressed to look out for something atypical.

The three mothers reported the following statements made in the postpartum period by professionals, including midwives, health visitors, obstetricians and general practitioners:

'You lost a lot of blood, your milk will be delayed.'

'It is rare not to get milk, I have never seen it.'

'You didn't lose that much blood; another mum gave birth at the same time as you and lost more than double you did.'

'You didn't lose that much blood, it must be something about you.'

'You're just a new mum that's tired.'

'It's normal to feel like this after what you went through.'

'There are other mums and babies on this ward to consider too.'

'This only happens in developing countries.'

'We never see this.'

'We weren't trained about this.'

'You're just anxious.'

'I've never heard of Sheehan's syndrome.'

Conclusion

Although they had differing histories all three women in this case study presented with failure to lactate in the early postpartum period. The literature describes failure to lactate as a key sign for early diagnosis of Sheehan's syndrome (Schrager & Sabo 2001, Dökmetaş et al 2006, Shivaprasad 2011) and the importance in reducing morbidity and avoiding mortality from this condition (González-González & Borjas-Almaguer 2018).

The experience of Mother A, with detection and treatment at day 5 postpartum, compared to Mother B, with adrenal crisis at day 13, highlights the importance of early treatment where hypocorticolism risks coma and death (González-González & Borjas-Almaguer 2018).

Although Mother B received emergency, lifesaving, treatment, she was significantly affected by this traumatic period of critical illness, in addition to a traumatic birth. Indeed, regardless of acute or chronic presentation, we argue that early detection is essential for the health, wellbeing and future life choices for all women.

From a cost perspective, early detection is likely to benefit health services by preventing the need for costly emergency admission and critical care treatment, as experienced by Mother B. The examples of communication experienced and reported by all three mothers suggest there may be a knowledge gap in UK maternity and health professionals, supported by an average delay in diagnosis of nine years in chronic Sheehan's syndrome (Jose et al 2019).

Overall, this rare and potentially life-threatening condition continues to occur in developed countries despite improvements in obstetric care (Kristjansdottir et al 2011) and there are calls for further research into its pathophysiology (González-González & Borjas-Almaguer 2018). Although it is an uncommon occurrence in countries such as the UK, it should be considered in any woman reporting signs or symptoms of pituitary damage with a history of postpartum haemorrhage (Jose et al 2019). The most common of these in the early postpartum period being failure to lactate (Sheehan 1937, González-González & Borias-Almaguer 2018).

In summary: *No milk? Think Sheehan's!*

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For more information on this topic please see search packs: PN29 Postpartum haemorrhage, PN66 Insufficient milk.